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## Book reviews

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### Genetics, the Fetus and our Future

Carmel Bagness, Hale, Cheshire, Hochland Hochland Ltd, 1998, 105 pages, £10.95 (sc).

Overall, I think this book is worth reading. It includes plenty of relevant facts, interesting quotations and conflicting arguments - the latter being an essential component. The more factual aspects of the remit are well organised and chapter one and the second half of chapters four and five are clearly laid out.

I recognise that philosophical and speculative issues are by their very nature less amenable to "organisation" within the confines of a short text. Nevertheless, I think the author only deals with these issues in a superficial manner. Philosophies are described but no philosophising is offered.

The author is clearly in favour of according greater respect to the "pre-embryo". In a book such as this I had hoped to be offered a deeper exploration of his/her own arguments together with some personal conclusions.

I have to question the author's understanding of in vitro fertilisation (IVF) and other assisted reproduction techniques. On Page 68 it is mentioned that genetic manipulation of the pre-embryo may prove unacceptable to many couples because of a low success rate of 10-15%. No mention is made of the variables that determine these harsh figures - and the fact that they depend inherently on numbers of attempted treatment cycles, maternal age and previous obstetric history. Nor is it mentioned that these quoted figures may be very different for couples who present for treatment because of a genetic disorder but have "normal" fertility.

I was surprised that the editor of this text had not corrected the poor use of English, which includes grammatical

errors and on occasions the incorrect use of language. This is a pity since it detracts from the overall impression and the potential importance of the take-home message for the reader, for example on page 71 the use of permeations instead of permutations and on page 84, elude instead of allude. In parts the prose is difficult to follow because the sentences are too long and unwieldy.

In summary, as a digest of the current state of opinion and the law and because it offers a practical understanding of the potential value of the study of the pre-embryo, the book has some merit. Readers will need to look elsewhere for in-depth discussion, analysis and the speculation that the title promises but does not address.

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### Ethics: The heart of Health Care (2nd ed)

David Seedhouse, Chichester, Wiley, 1998, 232 pages, £15.99.

The second edition of Seedhouse's well-known book comes ten years after the first. Like the first, the second edition will undoubtedly be well received by many, including teachers, students and practitioners of health care. Indeed one is tempted to suggest that, if a medical or nursing student read only one ethics text in the course of his or her training, then this would be a good choice. If students and practitioners of health care management, policy-makers and civil servants could also be persuaded to read it then this would be a bonus.

Seedhouse's style is highly personal and individual. He takes pleasure in being irreverent, provocative and controversial. This is most certainly not a textbook in the academic tradition of

neutrality and impartialism. Seedhouse has a clear agenda of his own and strongly held views about the nature of health care and the place of ethics within that domain. He is self-assured and self-confident almost to the point of arrogance, writing unselfconsciously of the "secret of the book's success", describing the work as "genuinely philosophy applied" and "long overdue". "Here at last," he says, "is the beginning of a philosophy of health" and one wonders what to make of his observation that his Ethical Grid "has not yet been universally adopted": perhaps he thinks this is only a matter of time. The book is likely to appeal more to health care students and young practitioners than would some of the more traditional texts in the area. Some readers, perhaps particularly those from a generation (or even two) before Seedhouse (we are told that he was at grammar school from 1967-74) may find some of his idiosyncrasies irritating rather than appealing. Others will welcome the humorous and un-stuffy approach (while many of us will share his fond memories of the Grafton Arms). Certainly few authors in the field will have given so personal an account of their own experiences of health care as Seedhouse gives of his recent diagnosis of and treatment for a benign tumour.

Statistically one should note that the new edition is some 66 pages longer than the first and although the number of chapters is the same the structure of the book is slightly different. The selection of case studies in part one has been increased from 10 to 15 and in part three the main decision making device of the Ethical Grid has been joined by a preliminary device called the Rings of Uncertainty. In other respects the text is very similar, although a certain amount of re-writing has taken place, some additional material has been added and the typeface and presentation has generally been improved. The index to the

second edition is far more comprehensive and this is certainly welcome.

As a working text for students and practitioners the book has many strengths. The first section gives a strong argument for the importance of ethics in health care, well illustrated by many relevant examples. The 15 case studies that conclude this section are particularly powerful and well chosen and could form the basis for many individual or group exercises, either within formal educational programmes or more informally within a team of professionals. The second section gives a useful overview of the main issues and theoretical approaches within health care ethics, again well illustrated by contemporary examples. The critiques of the main approaches to concepts such as the person and the various ethical theories are on the whole clear, reasonable and balanced, although his attack (not present in the first edition) on the four principles approach of Beauchamp and Childress and their supporters is scathing. The third section, introducing the Rings of Uncertainty and the Ethical Grid, once again provides an invaluable basis for discussion. As with the case studies (which can be used in conjunction with the tools) this section would be a powerful tool for group work. It would be gratifying indeed to think that a multi-disciplinary team or a group of students from the various health care professions might sit down together to work through some of the exercises suggested.

The most controversial aspect of the book is its highly personal approach. Seedhouse has a clear view of the nature of health and the role of health care, which he enthusiastically promulgates throughout the book. His perspective is in many ways appealing and no doubt most of us would prefer to be treated in the way he advocates. However, it could be argued that social and political trends in many parts of the world have driven the reality of health care practice, if anything, further away from the ideal that Seedhouse proposes. One assumes for example that he would not recommend the American health care system as a preferred means of achieving his view of health care - the optimising of human potential. However, some commentators have suggested that President Clinton's attempts at health reform (and the consequent threat to vested interests) were a major factor in the process that led to his recent impeachment hearing. Similarly the policies of the Conservative administration in the UK in the

decade or so prior to the last general election rested unashamedly on the principles of competition and market forces and sought to eliminate much of the social aspect of care. Seedhouse's vision may be attractive but he says little about the ways in which moral reasoning on the part of health care workers can stand against commercial forces or political conviction.

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## **Donor Insemination: International Perspectives**

Edited by K Daniels and E Haimes,  
Cambridge, Cambridge University  
Press, 1998, x + 185 pages, 1998,  
£37.50 hc, £13.95 sc.

Donor insemination (DI) is a neglected topic among social scientists. According to its editors, both established sociological experts in the study of assisted conception, this collection is the first of its kind. The reasons for this social scientific neglect must include DI's relatively "low-tech" character as a procedure (in comparison with so-called "new reproductive technologies" and the secrecy which has, historically, surrounded its use. As contributors to this book document, in the last decade the move to cryopreservation of semen in sperm banks, for example to permit screening for HIV/AIDS antibodies, has increased the technical complexity a little. And, following legislation or official guidelines, some information about semen providers and recipients and resulting offspring is now collected centrally in some countries, including the UK. But, at present, we still know very little about who has resorted to DI, for what reasons and in what circumstances, who has provided the sperm and why, or about the experience of those humans born as a result. This book fills some gaps and should be essential reading for anyone interested in the social and moral issues relating to assisted conception. For example, Daniels gives a valuable overview of research on semen providers and Blank an account of different approaches to regulation of DI in different countries. Haimes explores the changing representations of those conceived following DI during the twentieth century.

However, the volume also confirms explicitly and implicitly, by the restricted empirical material some authors have to draw on, the many unknowns that remain. One implication of our ignorance is that we cannot assume that some of the potential problems often attributed to DI are actually widespread. There may be thousands of people conceived as a result of DI who live their lives in blissful ignorance of their genetic origins and in harmony with their social fathers and thousands who live perfectly happily with full disclosure. In their contribution, the Snowdens, whose long term research with a small group of parents from one UK service constitutes much of what we know about DI, note that generally DI parents do not wish to talk about their decisions or their family life. The Snowdens attribute this to unresolved tensions and ambivalence, and possibly fear of their discreditable secret being revealed. But it might be that these parents simply do not see that there is anything to talk about. However, as Novaes suggests in a perceptive discussion of the medical management of DI, particularly in relation to France, the increasing prominence of genetic models of disease and human behaviour may be making anonymity of sperm providers and secrecy about a child's DI origins more problematic. But it does not follow that reducing anonymity will necessarily bring unalloyed benefits. Moreover, any "geneticisation" of society might lead to more general questioning of the legitimacy and value of DI, and, just possibly, more rather than less secrecy about resorting to it.

However, even if we should not assume that resort to DI or being conceived as a result of DI or secrecy about it routinely carries problems for individuals, the procedure clearly does raise ethical issues for society. Among those discussed in this book are the use of DI by those who are not (or not known to be) infertile but seek to conceive without engaging in heterosexual sex. Lasker, in her chapter on users of DI, notes that the proportion of this "unconventional" kind of DI recipient is likely to rise. New techniques to enhance sperm quality may make biological fatherhood more possible for subfertile men in stable couples. As Blank notes, it is not easy to frame legislation or guidelines to cover all the possible circumstances in which DI (as a medically managed procedure rather than self-insemination) might be requested. The medical profession

may be called upon to exercise "professional responsibility" in situations where it is by no means clear what would count as responsible action or where the boundary between responsible action and, for example, eugenics might lie. Finally, anthropologist Jeanette Edwards provides a cautionary tale for those who hope that "public opinion" might serve as a stable and uniform criterion against which options might be assessed.

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## Disordered Mother or Disordered Diagnosis? Munchausen By Proxy Syndrome

David B Allison and Mark S Roberts, New Jersey, USA, The Analytic Press Inc, 1998, 279 pages, £31.95.

Munchausen By Proxy Syndrome (MBPS) or Munchausen Syndrome By Proxy as Meadow termed it is one of the current controversial areas of child abuse. Its diagnosis or its very existence generates as much debate as that produced by the diagnosis of sexual abuse in the 1980s.

This book, whose authors are philosophers at the State University of New York, at Stony Brook, sets out to question the assumption on which the syndrome is based. They argue that the syndrome is essentially false and the evidence sustaining it insubstantial and logically flawed. This book is aimed at physicians - adult as well as paediatricians since it also considers Munchausen's Syndrome - and social and cultural theorists. The first part of the book is concerned with arguing that the construction of some disorders for example, witchcraft, hysteria and MBPS have more to do with medicine's - and in particular psychiatry's - attempt to contain and control challenging behaviour (especially in women) which has no obvious organic basis. In so doing the authors attack the philosophy and assumptions which underpin the *American Diagnostic and Statistical Manual - Mental Disorders* and the formulation of MBPS as a disorder.

In part two, the historical and textural precedents of Munchausen Syndrome and MBPS are traced. The authors argue that the diagnosis has

more to do with practical issues of administration, maintenance of social bias, the exercise of punishment and social control than it has to do with medical science. From their perspective MBPS has defined itself into existence by its extensive uncritical literature for example, incomplete case reports. It could of course be argued that this dependence on precedents, prior to formulation of generalisable hypotheses which can be tested, underpins much of medical science. One of the difficulties with MBPS is the lack of a coherent theory of causation; yet there are other medical syndromes for example, Alagille's Syndrome, (biliary hypoplasia) where specific causation may not be recognised.

The third part of the book is devoted to a criticism of what has become the American standard text on MBPS, namely Schreier and Libow's *Hurting For Love* and in particular its theory of motivation. There is detailed discussion of two American cases, namely the cases of "Christopher" and "Mrs Eldridge". Although the analysis of the cases is detailed readers who are not familiar with them will wish for a balanced summary of the facts. Ironically, this is a criticism which Allison and Roberts level at literature on Munchausen Syndrome By Proxy.

Overall, this is a thought-provoking book which, as the title suggests, is written from the mothers' perspective. It is written with passion but some might find the style too polemical for their taste. For example, an assertion is made that doctors in the US system "essentially created all the gynaecological myths and procedures directed against women in the first place" (page 184). Mother/child bonding is given as an example of a means of controlling women and re-establishing the centrality of the paediatrician and obstetrician. It could be counter-argued that much of the force of the bioethics movement of the last two decades has been directed against such biases. It could also be argued that welfare recipients, at least in the UK, can exaggerate or mis-report a child's symptoms in order to obtain benefits.

Perhaps understandably, given the perspective of this book, the ethical difficulties faced by professionals when they suspect deception do not receive much attention; even though, by accepting fabricated accounts professionals may "abuse" children by carrying out unnecessary investigation or treatment. Discussion of covert

video surveillance only appears towards the end of the book. Emmison's and Postlethwaite's analysis of MBPS as part of the factitious illness spectrum of disordered behaviour is not mentioned.

In their final chapter the authors acknowledge that parents may use medical means to abuse their children and emphasise the need for professionals to examine and attempt to understand the socioeconomic context, motivation and psychopathology. Whilst few would quarrel with these conclusions, I suspect that many, though having sympathy with the arguments in this book, would find them difficult to accept in their entirety. Perhaps there is a "third way"?

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## Defining Personhood: towards the Ethics of Quality in Clinical Care

Sarah Bishop Merrill, Amsterdam-Atlanta, Rodopi, 1998, 222 pages, £24.50.

The concept of a person is frequently invoked in medical ethics literature. Typically, it is appealed to in order to sustain a claimed difference in moral status between one (usually human) individual and another. Thus the concept is appealed to in the context of debates concerning the justification of abortion, the withdrawal of treatment from humans in persistent vegetative states, and the extent of our obligations to the severely cognitively impaired. Many contributions to these issues attempt to set out defining features of personhood, usually in the form of a list of necessary and sufficient conditions.

In this book the author is critical of, and rejects, such attempts. Her aim is to identify a number of "distinctive features" of personhood which will not constitute a set of necessary and sufficient conditions of the concept. The strategy by which these distinctive features are to be identified is through a survey of the views of a number of groups of language users (physicians, nurses, patients, and philosophy students) within the author's own linguistic community (the USA). Readers are

reminded in the book of the later Wittgenstein's dictum that "meaning is use" (page 116).

Unusually for a philosophical work, the book includes a description of a considerable empirical research programme, surveying the views of "several hundred" subjects (page 70) on the features which they associate with personhood. Thus the task referred to in the book's title of defining personhood is conducted by an empirical survey rather than philosophical *apriorism*. As noted, aspects of the philosophy of language of the later Wittgenstein supply the philosophical justification for such an approach.

Twenty-six distinctive features of personhood are put forward, ranging from being alive, and possessing rationality, to economic status and sense of humour. The author concludes from the empirical surveys that "no one feature, or single set of features, dominates the concept [of personhood]" (page 130), at least as this is understood by the groups surveyed. It is concluded, thus, that analyses of personhood in terms of necessary and sufficient conditions are at odds with ordinary usage. The survey is taken to suggest that the concept of personhood is, rather, "open-ended"; it is a fluid concept without fixed, determinate boundaries. This is not to say the concept is arbitrary, but rather that it is an "essentially contested concept" (page 143): differing groups have differing, if plausible, views about what is important to personhood.

How do these findings help contribute to a resolution of the kinds of problems of health care ethics referred to above? The author's claim is that "the distinctive-features theory does not solve the problem of the fetus or the comatose individual, it explains what the problem consists in, namely, the absence of features usually thought important to those asserting and recognizing personhood in our culture" (page 157). So the approach described in this book helps to diagnose what is going on in moral debates in which the concept of a person is invoked. Opponents, for example, in the abortion debate, will have differing conceptions of personhood. If I understand Sarah Bishop Merrill correctly, her view is that one cannot simply assert one's own view of personhood over another in order to win an argument, and any position on personhood will be objectionable in some way—being either too inclusive or too exclusive. If protagonists consider the

grounds for their differences less dogmatically there may be scope for a pragmatic agreement.

In criticism of the author, one wonders whether this conclusion requires the complex empirical survey described in the book. And, more critically, it is cogent to wonder what follows from the fact that a group of language users in a specific linguistic community hold a range of features to be distinctive of persons. The moral realm, as the author recognises, is a normative one. It cannot be shorn completely from descriptions of how subjects do in practice think about personhood, but the further question of whether they are morally justified in thinking in such ways seems a legitimate one. Determining meaning by reference only to current usage, seems to invite acceptance of the status quo, and hence of existing moral prejudices, and thus to be objectionable (for example would "personhood" have included women, children and slaves in Ancient Greece)?

In conclusion, this is a very wide ranging book. It includes interesting discussions of philosophical scholarship (notably the discussion of Locke's distinction between the self and the person), linguistic theory and medical ethics. But its Wittgensteinian-inspired methodology seems to this reviewer to call into question its conclusions.

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## Surgical Ethics

L B McCullough, J W Jones and B A Brody, New York, Oxford University Press, 1998, 396 pages, £35.00 (hb).

Many volumes have been written in recent years on medical ethics, but comparatively few have been focused especially on the ethics of surgery. Yet surgical practice offers a very sharp focus for many ethical principles. This excellent book is particularly timely because of the current re-evaluation of patients' rights and surgeons' rights, degrees of autonomy and the nature of consent. Of the 39 contributors, a majority are practising surgeons, who are having to make ethical decisions every day in their practice. This means that surgeons reading this book immediately identify with the situation and with the writers. However, ethicists without medical qualifications are

integral to the book and many chapters are written by two authors, one a surgeon and one an ethicist. The huge range of ethical issues are divided up into 19 chapters of a manageable length so that the book can be used as a reference for particular situations and for this, the extensive index is particularly useful. The book is not overburdened with references, but each chapter is well referenced independently.

Well-known subjects such as informed consent and confidentiality are covered, and the introductory chapter on principles and practice of surgical ethics is particularly valuable as it clarifies definitions and rights; but it is good to see that the authors do not duck the less defined areas of surgical practice, such as referral of patients to other physicians and the role of non-physician members of the team. The chapter on financial relationship with patients, although written from the standpoint of North American health care, outlines principles that are relevant to any health care system and, in this, the authors, quite rightly, claim that business aspects of medicine are also appropriate for ethical investigation. In many countries, it has been felt that business ethics are outside the remit of doctors, but the "market place" is impinging on our practice more and more. Of particular relevance to the British scene at present is the chapter on self regulation of surgical practice and research and it tackles such sensitive issues as "when should a surgeon retire?".

The book is full of useful practical advice and guidance, not least when it is considering patients who are family members, friends and colleagues; the warning to be wary of "kerb-side consults" is very wise! With each chapter divided into an analysis of principles followed by clinical topics the reader can see how to apply principles in practice. So often books on ethics are either too theoretical, on the one hand, or on the other hand give practical advice without the moral basis.

This book is an important contribution to the literature of medical ethics and it can be warmly recommended – not only to surgeons.

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## Medical Ethical Standards in Mental Health Care for Victims of Organised Violence, Refugees and Displaced Persons

Loes van Willigen, Utrecht, Royal Tropical Institute, 1998, 119 pages, £17.95

I opened this book, eager to discover the medical ethical problems of torture and systematic abuse of citizens, arising from "unethical interventions and unethical professional attitudes". At the end of the book I was little wiser. Of course, torture and abuse of human rights are unethical and an affront to human dignity, but what are these ethical standards which health care workers must adopt? Firstly, the book is only incidentally concerned with torture. Secondly, most of the issues which it identifies - autonomy, consent, cross-cultural approaches and the avoidance of cultural imperialism are common to a variety of settings. Indeed the book states, "these goals are generally considered self-evident....".

Perhaps the most valuable contribution questions the appropriateness of counselling, whose role in the care of people, following severe traumatic events, is already under scrutiny. People trust doctors, even when deeply traumatised, but the danger is that doctors may become, "the prime authenticators of suffering, legitimators of the sick role and gatekeepers to victim groups". The very existence of a special expertise in the care of traumatised victims is questioned. Whilst specialists will be needed to detect the more subtle consequences of physical violence, using only a special cadre of doctors and psychologists to detect mental trauma may be self-defeating. It de-skills other professionals from their major role in empathetic understanding and listening, and separates victims from their own cultural perceptions of pain and distress. Such specialists, by providing evidence in support of a request for asylum, may easily become merely an entrance ticket to another country.

War presents very severe moral problems and some of these are peculiar to the role of the doctor. Can ethical "rules", which the book advocates, ever be designed for a whole series of novel individual situations? Indeed, can medical acts ever be neutral in

war? By seeking to ameliorate its consequences, it could be argued that we are conniving with the war itself.

The book is least satisfactory in the chapters on research. A case study gives a classical example of unethical research, without illustrating problems peculiar to the situation. The study showed poor science, incompetent researchers, inadequate consent, lack of either cultural sensitivity or confidentiality, poor execution and poor analysis of results. It was not even published! In my view it is difficult to justify research for its own sake in torture victims, even if, in the long term, it may help future victims. It also runs the risk that research on the effectiveness of organised violence may become useful to those who practise it. Of course, treatment techniques must be carefully and thoroughly evaluated, but until these essential preliminaries have been completed, even the collection of data for apparently non-intrusive epidemiological studies from vulnerable, socially marginalised populations from different cultures should not be considered.

The book states that principlism is in retreat and that virtue ethics is beginning to creep back. Virtue ethics has much to offer in situations where ethical dilemmas are incapable of reconciliation. Also, in a post-modern culture, it is strange that ethical reasoning about why we should help such victims should lead to the Christian principle that anyone in need is my neighbour and deserving of my help.

The book is a useful contribution to European social policy. Its thirteen recommendations are all worthy of implementation by policy-makers. It is always useful to publish conference proceedings, if only for the benefit of those who would have liked to have been there themselves. For the medical ethicist however, even for one involved in mental health services, the book is likely to be less than satisfying.

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## Primum Non Nocere Today (2nd ed)

Edited by G Roberto Burgio and John D Lantos, Amsterdam, Elsevier Science BV, 1998, 171 pages, £93.10.

This book is an updated version of the record of a symposium on pediatric bioethics held in Pavia in 1994 and published later that year. The first edi-

tion well deserved its favourable reception and it is not surprising that the editors felt the need to restock the shelves and our minds with a reprint rather than a reprint. New contributors have appeared, mainly from Italy, and the USA, to cover the ethical aspects of rapidly developing areas of paediatric biotechnology (stem cell transplantation, cancer genes, and gene therapy). There is a new chapter on vaccination (Diekema, Marcuse) which puts well the ethical quandary between parental autonomy ("don't risk my child") and the public good (maintain herd immunity). The paper on therapeutic trials is now expanded to consider evidence-based medicine (EBM) as illustrated from their previous analysis of the algorithmic management of otitis media.

As there was no follow-up symposium this edition loses the element of discussion but it has gained a much needed index. Although expensive and selective this is an important contribution to paediatrics and to medical ethics.

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## When Doctors Say No. The Battleground of Medical Futility

Susan B Rubin, Bloomington, Indiana, Indiana University Press, 1998, 191 pages, US\$24.95.

This book is a polemical monograph. It aims to demonstrate that "physicians would not be justified in refusing unilaterally to offer, provide, or continue treatment based on their opinion that the treatment in question would be futile".

Expressed in these terms, the central thesis of the book may sound unrealistic or even absurd to many busy practising doctors. Is this then just another piece of doctor bashing by an armchair philosopher? Even the title sounds ominous.

In fact Rubin's thesis is more complex. For, as usual in futility debates, it all depends on what you mean by futility. After an introductory first chapter that sets the scene with a description of some publicly prominent cases and professional statements, she sketches out what futility is usually taken to mean and what criteria might be applied in deciding when treatments are futile. From here it is a

short and familiar step to discussing futility in terms of the value of the outcome (evaluative futility) and futility in terms of whether treatment even offers the (reasonable) prospect of an outcome (physiologic futility). In practice it may be easy to muddle these two together but the basic distinction has a certain common-sense appeal. Patients waste valuable resources and doctors prostitute professional integrity by offering treatments that have no prospect of working. Therefore, physiologic futility implies that doctors say "no" and patients don't get asked—just told. Chapter four, pretentiously entitled *The power of positivist thinking*, is the central and most important chapter of this book. It is here that Rubin argues that the predictive claim of physiologic futility "always includes an evaluative component". This conclusion is reached by caricaturing factual statements as "positivist" (the "autonomy of knowledge credo"), in contrast with a "social constructionist model", while conceding that this theory and orientation is "not perfect". We are not told how imperfect.

The final chapter then argues that, despite all this, the author has "not argued against a physician's right ever to refuse, offer, provide or continue treatment desired by patients. Nor have I argued against society's role in setting limits". The answer lies in society's involvement in setting the values within which medicine works. Treatment can be refused if there is an "overwhelming consensus" so that the doctor's refusal is socially sanctioned. The book ends with a useful 23-page bibliography, almost entirely American. Perhaps this is a largely American problem: the battleground of medical futility isn't where most professionals or patients are preparing for their biggest fights in Europe.

The weakness of the book is its failure to convince the reader that the central thesis really makes any difference. For whether treatment is to be stopped because of an "overwhelming consensus" that it is useless or because it is "futile" will strike most doctors at the bedside as an irrelevant word game. It will presumably still involve the doctors' collective or individual values insofar as these determine the acceptance of overwhelming consensus. Medicine is a moral enterprise and the book would have been better balanced if that had been explored in more detail. Instead there is: the impression of a crude epistemology that contrasts positivism with "social constructivism", as if that is all that philosophy can offer; inelegant English; intrusive use of the first person, and a failure by the author to answer the objections to her thesis already in print, included in the bibliography, and, indeed, reviewed previously in this journal. Rubin has offered an interesting read but not a balanced one.

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### **Access to Experimental Drugs in Terminal Illness. Ethical Issues**

Udo Schuklenk, New York, Pharmaceutical Products Press, 1998, 228 pages, US\$60.

Availability of, and equitable access to, therapeutic drugs have never been more topical or eagerly debated than at present. Public discontent, professional turmoil and political imperative have spawned exhaustive dicta on these issues, describing quasi-innovative frameworks for consensus such as evidence-based practice, clinical governance and integrated health care. However, controversies over autonomy, resource allocation and discrimination remain. In his book Udo Schuklenk proposes to highlight some of these issues, and more, in the context of those suffering from terminal illness, with particular emphasis on ethical issues arising from current health care practice.

A thorough critique of such subject matter requires one to bridge the apparently inextricable but potentially disparate disciplines of ethics and clinical/pharmaceutical practice. That the author aims to achieve this so explicitly and precisely is both refreshing and reflective of his knowledge base. At the outset Dr Schuklenk explains his intent to explore the issues of the title using AIDS as the context of discussion and argument. He contends that observations made and conclusions drawn are applicable to the wider community with terminal illness, the choice of AIDS acting simply as a "real-world case study". The framework he chooses leads us logically and resolutely through ethical theories of paternalism and autonomy, appraisal of clinical trials and issues of

cost, as all the while the author reflects on their implications for availability of experimental drugs to those with incurable disease.

The section addressing issues of paternalism is extensive in its breadth of thought, discussion and selected criticism of such theory. The author summarises precisely the often complex and conflicting paradigms of strong and weak paternalism espoused by Kant, Mill and Young among others. Whilst finding consistency and plausibility in the paternalists' definitions of autonomy, he faults their reasoning on intervention. Mill, for example, considered it reasonable to intercede if the individual was unaware of potential adverse reactions. The author assumes that the *level* of risk is irrelevant, only that the *possibility* of risk be clear. It is on the strength of this assumption that he disclaims the right of any paternalistic interference. He contests that AIDS patients are well informed and articulate. Hence they are ethically capable of the authentic decision to take undefined risks with experimental drugs. Several issues are of concern in this context. The assumption that magnitude of risk is irrelevant to those with incurable disease, because nothing could be worse than their inevitable death, represents a tenuous nexus for the recurrent arguments in favour of accessibility to unproven drugs. The expectations of those with terminal illness in terms of prognosis, treatment potential and quality of life are often surprisingly high, suggesting that levels of possible treatment-burden rank as highly as potential benefit. The author also imputes a high level of knowledge and understanding to his patient group. This may be true of an articulate minority of AIDS sufferers but neglects the reality of the majority, including intravenous drug abusers and those in the developing world.

In addressing issues of restricted treatment access via clinical trials, Dr Schuklenk uses a landmark trial of AZT therapy as a template for discussion. He adeptly describes the nature and clinical pitfalls of the trial and uses it as an opportunity to address ethical issues surrounding general conduct of clinical trials. It is an excellent exposé of devastatingly poor research practice and clearly defines the parameters for acceptable trial design and implementation. The arguments made in this chapter sit easily with the concept of well-constructed clinical trials which are all-inclusive,—akin to the UK paediatric oncology paradigm where

most treatment is trial-based—allowing the greatest accumulation of knowledge and flow of information. Surprisingly the author concludes that experimental drugs of no proven value, should be easily accessible to terminally ill patients because all current clinical trials are coercive, restrictive and mis/uninformative, whilst terminally ill patients do not have the time for altruism. This assumes a likelihood that unproven drugs have any potential benefit, and certainly fewer burdens, although the potential for misinformation, unfathomable clinical outcomes and immeasurable impact on quality of life would appear greater with unfettered access. Thus, contrary to his conclusions, the author does not clearly show that, on the basis of historically bad research practice, lack of prohibition would equate with patient autonomy.

Having argued in favour of free access to experimental drugs for the terminally ill on the basis of autonomy, incompetent trials structure and inadequate “standard treatment” (prognosis can’t get any worse), Dr Schuklenk does not shirk issues of cost. He argues in favour of absorption of these costs into health care budgets, at least to the same level as standard treatments (which, he argues, don’t work anyway) in societies without universal health care. That terminally ill (and specifically AIDS) patients may represent marginalised sections of society further mandates for such action, although the impact on other services in the “real world” of rationing is not discussed. The section ends with a concise, well-judged review of the essential need for adequate information-gathering and dissemination to all sections of the community.

There is much of merit in the structure of this book and ultimately it is a passionate, if not unflawed, argument in favour of free access to experimental drugs for AIDS patients. However, discussion frequently centres on a small, specific subgroup and the conclusions drawn do not transfer easily to the greater population of those with terminal illness. In that sense the content does not fulfil the expectations raised by the title, and those with an appetite for a broad, objective look at the many ethical issues surrounding therapeutics in the terminally ill may not be fully satiated by this contribution.

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## **Informed Consent: Patient Autonomy and Clinician Beneficence within Health Care (2nd ed)**

Stephen Wear, Washington DC,  
Georgetown University Press, 1998,  
200 pages, £15.75.

The appearance of a second edition of Stephen Wear's 1993 book is a well-deserved compliment to the first edition. Those who were convinced by the operational model of informed consent presented in the first edition will be pleased to learn that the new edition does not include any substantial changes. As the author himself indicates in the preface the basic argument is the same as are the main conclusions.

For the benefit of those who are not familiar with the first edition (reviewed in these pages in April 1995), the author's main aim is to offer a realistic model of informed consent which would be of real value to practising clinicians. “Mention informed consent to a clinician and my experiences is that you are more likely to get a groan, as well as talk about the ‘myth of informed consent’”. Seldom will one encounter a clinician who sees informed consent as simply a useful tool for medical management” (page 2).

Wear's model consists of three stages. During the first two the physician provides information to the patient, whereas during the third, and interactive, stage the patient should be pressed, if necessary, to provide some feedback, so that the doctor can see whether the patient has sufficiently understood what is at stake and is thus able to reach a better informed decision. This is particularly important when crucial, value-charged issues are involved.

The second edition contains a short new section called The clinician's discretion (located near the end of the book), where the author compares his model of informed consent with the “transparency” model of Howard Brody. It is the third, interactive stage in his model that he sees as the major difference from Brody's. The second edition also attempts to remove any confusion or lack of clarity in the text to which critics have drawn the author's attention. It is to be hoped that the practitioners for whom the book is intended as a useful “tool” will find its second edition to be a

“perfected tool” which will contribute to the silencing of the groaners about informed consent.

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## **The Changing Face of Health Care**

Edited by John Kilner, Robert Orr  
and Judith Shelley, Michigan, Wm B  
Eerdmans Publishing Co and Cum-  
bria, Paternoster Press, 1998, 314  
pages, US\$19.00.

In the words of the editors, this book is “an honest attempt to grapple with the often-conflicting matters involved in the changing face of health care” (page xii). This “changing face” refers specifically here to the American style of managed care. However, by implication it also applies to other health care systems where resources are being rationed and schemes have been in put in place to achieve this end.

Managed care has received much criticism, mainly from those health care practitioners who work at the coalface. Managed care has changed the face of health care because it restricts the autonomous practice of physicians to acting in what they see as the best interests of patients. Under managed care, health care interventions have to be authorised by business enterprises (HMOs), health has been commodified, profit has become a driving incentive and, as this book describes, Christian principles and responsibilities are being compromised.

This book urges Christians to understand and debate the issues raised by managed care and the allocation of health care resources and to become actively involved by supporting the good aspects and reforming the bad. I do, however, think that some of the suggestions made by the contributors arise from a rather idealised view of the world and of human nature.

*The Changing Face of Health Care* is organised into five parts with a glossary and a concluding chapter written from a British point of view. This chapter, written by Stuart Horner, adds credence to the book by assuring the reader that problems such as those experienced under managed care, are global and not country-specific. The first part of the book includes the reflections of personal experiences of managed care. Part two provides insight into the practices of medicine and nursing and also looks at concepts

of justice and rationing. The third part discusses the concerns raised when economics and business encroach on patient care. Part four concentrates on the impact of health changes in particular settings, such as mental health, long term care and minority communities. This part concludes with an interesting chapter on the impact of managed care on malpractice. The fifth part attempts to provide some constructive responses to the challenge of managed care but I personally do not see these as achievable on a large scale.

Throughout the book there are many biblical references that sometimes enhance the argument, but often do not help with any definition of the problems inherent in managed care, and how to solve them.

Perhaps one of the most useful contributions to this book is that of Kenman Wong who very coherently dis-

cusses both business and medicine, showing that for each to be ethical and successful they do not necessarily have to operate at opposite ends of the spectrum. He concludes his paper by giving "some examples of the ethical responsibilities that can be assigned to managed care organisations based upon business ethics" (page 147).

This book makes a useful contribution to the discussion of managed care but with so many contributors some of the discussion is repetitious. After reading this book however, one does feel the need to try and address the conflict between the rights of the individual and the requirements of a broader collective society (page 292).

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